Summary from Workgroup Session A1: "Obtaining and Sending Transplant Clot Samples"

The following items were discussed during this breakout session:

- Payment for sending the specimens back to the transplant center
 - Resolution; UMD already pays for their patients. JHH will begin within 2 months
- What is included in the kits?
 - o The mailer, labels for the patient, the red top tube or tiger top tube.
- Should Dialysis Units spin the sample
 - O It is helpful if they do to reduce hemolysis, but it is not necessary. It is more important to send the specimens the same day they are drawn rather that hold them at the units. If you must store them for any length of time, do so in a refrigerator. Do not freeze.
- Provide a Dialysis Center Liaison person to each of the laboratories
- Improve communication
 - o Dialysis units say they have difficulty reaching a real person.
 - Newsletter article detailing the monthly specimen procedures
 - Dialogue to routinely exchange clinical information and patient status between TPL centers and Dialysis Units
 - o Routine exchange of lists with the dialysis units so everyone is on the same page
- Assignment of responsibility with regards to transplant patient management. (This was sort of off track with our session but stemmed from the inability of the dialysis units to contact the transplant centers.)
- Formalize the requirements so they are the same across both centers.
 - This will take a little bit of effort on the parts of the transplant centers to communicate effectively exactly what is required.

<u>This session was facilitated by:</u> Lisa Owens, RN, BSN of University of Maryland John Hart, MBA, CHS of Johns Hopkins

Questions about workgroup session A1 summary?

Please contact: John Hart, Email: hartjm@jhmi.edu, ph: 410.955.3600

Summary from Collaborative Workgroup Session B1: "Coordination of information about compliance, psychosocial and financial/coverage"

The following items were discussed during this breakout session:

- Idea that patients should be encouraged to take control of their care.
- Some concern about patients who need added measure of support
 - o Recommendation that dialysis and transplant staff assess patient's individual abilities at any given time during the transplant process
- Concern about raising issues of "compliance" about patients.
 - O Noted that mentioning compliance issues can be through informal conversation, acknowledgement that raising compliance issues was important so that transplant social workers could have more in depth consultation with potential patients, and may allow them to develop an "action plan" to address issues throughout transplant.
- Acknowledgement that the transplant liaison at the dialysis unit should always have regular communication from the transplant center about patient status
- Transplant center to consistently communicate to dialysis center what information needed on patient so that transplant is not delayed
- Dialysis-transplant community needs a tool to help track the status of the patient.
 - Discussion about a "Patient Status List" tool, a list that is distributed to dialysis units from transplant centers every other month
 - Decided that this tool should be provided to all dialysis units and that it should include demographic and insurance information in addition to the status of the patient.

Next steps:

- UMMS collaborative workgroup facilitators to confer with UMMS transplant leadership about creating a patient status tool
- JHH to revise format of its current patient status list to include revisions from collaborative discussion & send lists to all dialysis units in the state of Maryland every other month.
- Transplant liaisons in dialysis community to review patient status lists/ provide feedback on information that is inaccurate or incomplete on the list.

This session was facilitated by:

Zendy Williams, LGSW & Chelsea Quinn, LGSW of University of Maryland Rose Mary Gall, RN, BSN of Johns Hopkins

Summary from Workgroup Session A2:

"Coordination of information about patient status: waiting on the list, hospitalizations or changes in health status, death, transplantation, etc."

The following items were discussed during this breakout session:

- Wait time for each blood group
- What dialysis centers would like from the transplant centers in terms of information, contacts, etc.
- How dialysis centers can take a more proactive role in referring patients for transplant evaluation
- How & when the dialysis units & patients should be contacting the transplant center
- What happens if a patient declines an organ offer
- Questions arose re: the Network expectation of transplant education in the dialysis facility and what qualified, i.e. handing the patient a pamphlet vs. more detailed info.
- There was discussion about making sure each facility was aware that a policy for managing transplant referrals was in place
- Discussion re: who in the facility was more comfortable, experienced, interested, appropriate to be the transplant liaison in the facility, generally RN vs. MSW?
- Sample medical record transplant documentation tools were shared

Next steps:

- It was discussed how email is the most expeditious way to contact the transplant centers. This was more of a learning how we each work & how to work together better.
- Dialysis units requested that when transplant centers send them a copy of the patient's transplant evaluation "workup" still to be completed letter, that the transplant center also includes the transplant physician's notes from his/her evaluation of the patient
- Transplant Centers to conduct more patient in-services about transplant
- Establish who the dialysis facilities can contact in order to get a copy of the hospital transplant policy which the Network requires each facility to have on site.

This session was facilitated by:

Janet Anderson, MSW, LGSW of Davita Lisa Owens RN, BSN of Univ. of Maryland Kate Knott, RN, BSN of Johns Hopkins

Summary from Workgroup Session B2: "Developing education materials to address patient questions about transplantation"

The following items were discussed during this breakout session:

- Education about the process of evaluation and workup needs to be reinforce
- Consistent "introduction to transplant and getting through the workup" program would help the dialysis nurses and patients all.
- Dialysis staff request information to help the patient with understanding how to decide whether or not transplant is the therapy for them.
- Identification of patients' frequently asked questions & concerns
 - How soon until the transplant?
 - Who is the transplant contact person?
 - O How much transplant cost?
 - Does the patient have adequate coverage?
 - Will the insurance cover the transplant?
 - How long will I be in the Hospital?
 - o How long will the kidney last?
 - o How will Transplant improve the patient's quality of life?
 - Patients hear horror stories of other patients (only transplant role models are the failures.)
- Identification of teaching methods such as posters, flyers, to help teach patients about transplant.
 - Video
 - o Mentoring (have successful transplant patients visit dialysis units)
 - Written materials
 - o Interactive and visual materials
 - Should be realistic
 - Should be balanced pro's and con's

Next steps:

Develop an email group to continue to share and collaboratively develop patient education.

This session was facilitated by:

Linda Wood, RN, BSN of University of Maryland Susan (Peters) Humphreys, RN, MS of Johns Hopkins